



SOME COMMENTS ON THE FUTURE OF HUGO

Paper for Council discussion

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1. On the general role of HUGO:

HUGO, we all agree, at this stage in its existence, is restricted to acting as a facilitator, not a manager, of Human Genome Project (HGP) activities. As such it serves as the interface between international groups of scientists and specific national and international funding agencies. Consider, for example the Moscow SBH meeting. The initial drive came from Mirzabekov, Galas, and a few other interested scientists. HUGO coordinated activities in the USSR, the US DOE, and Western Europe to make the meeting a reality, to make sure that all truly interested parties were contacted and invited, and HUGO assisted in ensuring smooth local logistical support. Without HUGO's participation, it is unlikely that the meeting could have been organized on such a short time scale; key European participants might not have been identified, and the meeting, which ended in a firm resolve to promote extensive international collaboration in this key area, would almost certainly have been less successful, if it had occurred at all.

2. HUGO as an Information clearinghouse:

It is impractical in the genome project to deal with key areas of

technology and information by a series of bilateral arrangements between countries or funding agencies. Alone among all the entities involved in the HGP, HUGO has access to all active scientists working on the HGP, and it has access to all relevant funding agencies. Its major participants, on Council, and various committees, represent a good fraction of the most active investigators of the HGP. In some cases, such as the organization of CCMs, this places HUGO in a uniquely favorable position to implement international cooperation and information sharing, directly. HUGO's current resources are quite limited, and it must select only certain issues for its active participation. However, even if the mechanism for implementation of specific cooperative efforts does not involve HUGO directly, HUGO serves as the best available source of information about current activities, needs, and possible solutions. For example, it was at a HUGO meeting that the range and diversity of current cDNA activities first became known to both scientists and funding agencies. Had this meeting not taken place, it is likely that far more serious rifts between different cDNA endeavors might have formed, before these became internationally known. HUGO cannot resolve these cDNA issues alone, but it can continue to play a role as a forum for international discussion among the scientists who are actually participating in this work. Regardless of the eventually outcome about private sector rights to cDNA information, HUGO is proceeding to work with key scientists to design and help them implement methods for sharing cDNA data among basic researchers, unclouded by issues of commercial ownership.

3. HUGO as an implementor:

The eventual role of HUGO will, of necessity, be decided by the scale of its financial support. If, eventually, HUGO receives sufficient funding direct from international and national funding agencies, it might be able to provide a stable structure for coordinating, perhaps even managing, international aspects of the project such as databases, a large body of specific workshops, and a forum for educating the broad community of scientists and the lay public about key intellectual, social, ethical, and legal issues raised by the HGP. At present, with its more limited support, HUGO has chosen to try, with small groups, to identify those aspects of the project which can be assisted by international discussion; i.e, those issues that are truly international in nature.

4. Without HUGO what would happen:

The HGP is plagued by a plethora of meetings, workshops, publications, and all too often, politics. HUGO is playing a major role in trying to restrain duplicative activity, by being rather conservative with its official imprimature for genome activities. HUGO has no legal authority in this, but the size and standing of its membership gives it considerable clout. For example, SCW's are a necessary but a very expensive part of the HGP. Failure to coordinate activities to organize SCWs in the US, Europe, and Japan would lead to a disastrous situation of too many poorly funded and poorly attended meetings, with potential divisive outcomes. HUGO today is not in a position to manage these meetings; nor does it have the mandate to do this. It has, however, begun to play a key role in trying to encourage their structure along models of successful previous SCWs, in promoting an orderly schedule of these meetings, in ensuring broad geographic distribution of both meeting sites and participants, and in stimulating new activities to organize orphan chromosomes. Without HUGO, some other international group would have to be constituted for this very task.

5. HUGO's major past accomplishment:

The difficulties in making the transition from a successful and popular (but financially unmanageable, and arguably archaic) HGMW format to a new format for international coordination of mapping efforts were major and should not be underestimated. But HUGO has now succeeded in doing this, without leaving too many scars, and without slowing the momentum of that mapping effort at all. Frankly, it is hard to see how, without the active participation of HUGO, how this transition could have occurred. HGMW would have collapsed, and considerable time would have elapsed before a replacement could have been reconstituted.

6. Organizational problems and their potential solutions:

The difficulties of managing an international organization with a limited funding base were grossly underestimated by all of us. We now realize that a looser affiliation of several regional efforts, with coordinated policies, but separate tasks for specific implementation, will work much more effectively. We are moving towards that posture rapidly, by involving specific council members directly in specific programs and specific office activities.

7. Who Is HUGO:

To date most of the daily work of HUGO has been handled by several paid employees in the London and US offices, and by considerable pro-bono contributions of a few of the officers and council members. Much of their efforts have been to establish and nurture specific HUGO committees. Some of these committees have been more successful than others. There is every reason to believe that HUGO is now in a position to focus its efforts on those areas where it has the capacity and the proven capability to provide useful coordination.

8. Role of HUGO regions:

To be a healthy, functioning international organization, HUGO needs active offices in several regions. It needs mechanisms to coordinate the activities of these offices. It needs a plan to assign specific responsibilities to these offices. Naturally these issues depend on the particular HUGO officers and employees at any one time. However a general scheme is evolving, based on past experience. Council will meet twice a year and will continue to set general HUGO policy; individual council members will play specific roles in assisting regional offices to implement that policy. An executive committee formed from the officers and several additional members of council has been delegated authority to act on council's behalf, on most issues. Specific members of council (plus some others) will form the local trustees for each regional office. They will provide programmatic oversight for the employees of these offices. HUGO officers, and the principle employees of the regional offices are in daily contact by telephone and telefax. This is the major mechanism that is currently serving to manage the daily affairs of HUGO. Until such time as funds exist to hire high level senior scientist-administrators, this mechanism will continue. The original notion that one such individual could oversee all the offices, simultaneously, now seems impractical, because the geographic spread of these offices, and the differing legal and social milieus in which they operate, render this task an impossible one.